908 KAR 2:120. Kentucky Early Intervention Program evaluation and eligibility.

RELATES TO: 20 USC 1471-1485

STATUTORY AUTHORITY: KRS 194A.050, 200.650-676

NECESSITY, FUNCTION, AND CONFORMITY: The Cabinet for Health Services is directed by KRS 200.650 to 200.676 to administer all funds appropriated to implement provisions, to enter into contracts with service providers, and to promulgate administrative regulations. This administrative regulation sets forth the provisions for evaluation and eligibility policies pertaining to First Steps, Kentucky's Early Intervention Program.

Introduction

Evaluation is a service provided to Kentucky's infants and toddlers suspected of/or having developmental delays or who have Established Risk Conditions. Evaluations includes certain procedures used by appropriate qualified personnel to determine the existence of a Developmental delay or an Established Risk Condition and to establish eligibility for early intervention services.

This chapter is meant to clarify the evaluation process and provide guidelines for First Steps evaluators, Point of Entry Personnel, and service coordinators. It should be read in entirety to fully understand the concepts and direction for Evaluation services.

First Steps supports family-centered, geographically accessible evaluation services. The evaluation process should include appropriate, reliable, and non-discriminatory procedures, chosen on the basis of individual need and administered by appropriately trained personnel. Evaluation may be one of the first contacts a family has with First Steps and it should be performed in an expedient and family-friendly manner. Parents and professionals working together as partners maximize the success of the evaluation process.

Section 1. Evaluation.

(1) Every child shall have an evaluation to determine eligibility:

Best Practice Guideline: For children with an established risk condition, a medical evaluation which establishes a diagnosis is what determines eligibility.

- (a) A primary evaluation shall occur within forty-five (45) days after receipt of the referral; or
- (b) If primary evaluation does not occur within forty-five (45) days due to illness of the child or a request by the parent, the delay circumstances shall be documented.
- (c) When a family is referred for evaluation by the initial service coordinator and the family is under court order or a social services directive to enroll their child in First Steps, the court or social service agency shall be informed within three (3) working days by the initial service coordinator, if the family refuses the evaluation.

Best Practice Guideline: It is particularly important that under these circumstances First Steps personnel assess the situation and insure that the full resources available to address the circumstances are utilized.

- (d) Child records of evaluations transferred from out-of-state tertiary or developmental evaluation centers shall be reviewed by the initial service coordinator and shall be utilized for eligibility determination when:
 - 1. The records meet First Steps evaluation time lines; and
 - 2. The records contain all developmental evaluation information required by First Steps to determine eligibility.
- (2) The primary level evaluation is the first level in the First Steps evaluation system that shall be utilized to determine eligibility, developmental status and program planning:

Best Practice Guideline: The primary evaluator should include recommendations for outcomes.

- (a) The primary level is used when there are no existing evaluations available within the allowed time limits:
 - 1. For children under twelve (12) months of age, evaluations shall have been performed within three (3) months prior to referral to First Steps;
 - 2. For children twelve (12) months to three (3) years of age, evaluation must have been performed within six (6) months prior to referral to First Steps;
- (b) Primary level evaluations shall provide evaluation in all five (5) developmental areas;
- (c) The primary evaluation shall be provided by a team consisting of a physician or nurse practitioner and a primary evaluator approved by the cabinet;
- (d) Primary evaluation shall be multidisciplinary and shall minimally include:
 - 1. A medical component completed by a physician or a nurse practitioner that includes:
 - a. A history and physical examination;
 - b. A hearing and vision screening; and
 - c. A child's medical evaluation that shall be current according to the following:
 - (i) For children under twelve (12) months of age, the medical evaluation shall have been performed within three (3) months prior to referral to First Steps; and
 - (ii) For children twelve (12) months to three (3) years of age, the medical evaluation shall be performed within six (6) months prior to referral;

Best Practice Guideline: The hearing screen may consist of the standard physician hearing screening as well as newborn hearing screening such as Algo II screening test or the OT Acoustic Emissions Test. The vision screen may consist of the standard physician vision screening as well as the red and corneal light reflex, and the cover/uncover eye focused on a single object. All children meeting specific guidelines will receive the First Steps hearing checklist (Required Form 2) performed by the Point of Entry in the initial intake process.

Best Practice Guideline: A child is considered Medically Fragile(Attachment A3) when complex medical conditions may put them at risk for a catastrophic event during <u>evaluation</u>, <u>assessment</u>, or <u>treatment</u>. This condition is not synonymous with Established Risk, although diagnoses may overlap. Extra caution is needed during the initial phase of unfamiliarity and potentially unstable medical conditions. IT SHOULD BE RECOGNIZED THAT MANY OF THESE

CHILDREN WILL IMPROVE AND STABLILIZE AS WELL AS BECOME INVOLVED IN STABLE ROUTINES WITH CAREGIVERS AND THERAPISTS.

When a child is considered medically fragile by the nurse practitioner or physician, the following steps are recommended as part of the intake at the POE.

- The POE nurse should be involved with or consulted about children who meet the medically fragile definition as identified by a nurse practitioner or physician or their conditions are on the medically fragile list.
- A list of limitations from a physician familiar with the child should be part of the record or IFSP. These limitations should be updated periodically.
- The service coordinator, family and/or primary evaluator may consider it appropriate for a nurse to be present during the primary evaluation or the initial implementation of therapies, to monitor or assess for signs or symptoms of stress or intolerance of therapies.
- Alternative testing strategies for evaluation purposes should be considered that would not stress the infant, such as parent report instruments.
- 2. A developmental component completed by a qualified primary evaluator that utilizes standardized measures and the results interpreted to the family prior to the IFSP team meeting.
- (3) Verification of a child's eligibility for services shall be based upon the review by parents and professionals at the initial IFSP meeting;

Best Practice Guideline: All members of the IFSP team should be involved in determining eligibility.

Best Practice Guideline: When norm referenced testing reveals a delay in one area of development which does not meet eligibility criteria, a more in-depth standardized test in that area of development should be requested when all of the following are evident:

- A. The Primary Evaluator, IFSP team and /or the family has concern or suspects through observation and/or parent report that the child's delay may be greater than the testing reveals, and
- B. A more sensitive test tool may reveal a standard score which would meet eligibility criteria, and
- C. Only one area of development is of concern.
- (4) Reevaluations shall be provided when a child's eligibility warrants review or a new condition is suspected or becomes apparent;
 - (a) The need for reevaluation is determined by the IFSP team;
 - (b) Reevaluations shall be obtained at the level of evaluation determined to be needed by the IFSP team.

Best Practice Guideline: Reevaluation may not be used to address concerns that are medical in nature. Reevaluation may not be used to provide periodic, ongoing follow-up services for post testing nor testing for transition. Children performing within age appropriate milestones in all five areas of developments should be reviewed by the IFSP team for consideration for re-evaluation.

- (c) Based on the result of the reevaluation, the IFSP team shall:
 - 1. Continue with the same level of services; or
 - 2. Continue with modified services; or
 - 3. Graduate the child from First Steps services because child is developmentally age appropriate; or
 - 4. Continue eligibility with a tracking and maintenance approach and reevaluate in six (6) months.

Best Practice Guideline: For children with an Established Risk diagnosis, Options # 1,#2,or #4 should be considered, since eligibility is not an issue.

- (5) An intensive evaluation is the second level in the First Steps evaluation system that shall be utilized to determine eligibility, medical or mental diagnosis, program planning, or plan evaluation:
 - (a) A child shall be referred for an intensive level evaluation when:
 - 1. A primary evaluator identifies a need for further developmental testing necessary to clarify a diagnosis to further define the child's developmental status in terms of a child's strengths and areas of need; or
 - 2. A child doesn't meet eligibility guidelines at the primary level, but a primary evaluator or the family still have concerns that the child is developing atypically and a determination of professional judgement is needed; or
 - 3. The IFSP team requests an intensive team evaluation for the purposes of a diagnosis or to make specific program planning and evaluation recommendations for the individual child.

Best Practice Guideline: The decision to refer for an Intensive Evaluation could be considered when: the diagnosis of Autism is suspected; extreme aggression, hyperactivity or anti-social behavior is exhibited without a diagnosis to explain the behavior; child qualifies at the Primary Level, but the Primary Evaluator and IFSP team suspects that a child may have an undiagnosed Established Risk condition; child scores two(2)standard deviations below the mean in the area of motor development, but has no diagnosis to explain this delay.

Best Practice Guideline: Direct physician referral to the Intensive Clinic is not encouraged. The child should be directly referred to the POE if eligibility is not established. If the child is currently in services, the IFSP team should be involved in the decision to refer to the Intensive Clinic.

- (b) A record review shall be done by an intensive team at the request of the IFSP team whenever:
 - 1. There is a question of eligibility;
 - 2. Concern for a child's condition; or
 - 3. Effectiveness of a child's program plan.
- (c) An intensive level evaluation shall be provided by an approved team consisting of:
 - 1. A board certified developmental pediatrician; or
 - 2. A pediatrician who has experience in the area of early childhood development; and
 - 3. One (1) or more qualified developmental professionals.
- (6) Family rights must be respected and procedural safeguards followed in providing evaluation services:
 - (a) Written parental consent shall be obtained before conducting an evaluation or assessment by the evaluator or assessor respectively.
 - (b) If a parent or guardian refuses to allow a child to undergo a physical or medical examination for eligibility because of religious beliefs:
 - 1. Documentation shall be obtained in the form of a notarized statement. The notarized statement shall be signed by the parent or guardian to the effect that the physical examination or evaluation is in conflict with the practice of a recognized church or religious denomination to which they belong.

2. With the presence of a professional judgement of developmental delay that determines the child to be eligible, First Steps shall provide, at the parent's request, services that do not require by statute proper physical or medical evaluations.

Best Practice Guideline: The POE initial service coordinator should explain to the family that medical refusal may result in denial of services such as Physical Therapy, Occupational Therapy, and some speech therapies, which require a medical assessment on which to base treatment protocols.

(7) A written report shall be completed for every level of evaluation including record reviews.

Best Practice Guideline: Factors that may have influenced test conclusions should be noted (e.g. fatigue, hunger, short attention span, speech articulation problems.) Such qualifiers should be stated in the narrative report along with the parent's assessment of the child's performance in comparison to abilities ordinarily demonstrated by the child in more familiar circumstances.

- (a) The minimum components are:
 - 1. Names of evaluators and discipline;
 - 2. Name and telephone number of contact person;
 - 3. Identifying information that includes:
 - a. Age;
 - b. Date of birth;
 - c. Date of evaluation;
 - d. Evaluator's affiliation, and professional degree;
 - e. Referral source; and
 - f. Reason for referral or presenting problems.
 - 4. Tests administered or evaluation procedures utilized and purpose of instrument. No one (1) method of evaluation shall be used, but a combination of tests and methods shall be used;
 - 5. Test results and interpretation of strength and needs of child;
 - 6. Test results reported in standard deviation or developmental quotient when such instrumentation is required;
 - 7. Eligibility;

Best Practice Guideline: Families are frequently anxious about the results of the testing procedure. When the primary evaluator has <u>completed</u> the initial testing and <u>scoring</u> of the test and the child has <u>clearly</u> met criteria for eligibility; the evaluator may inform the family that the scores are within eligibility requirements for the First Steps Program. Explanation of the child's strengths and areas of concern should be discussed with the family prior to the IFSP meeting and addressed at the first IFSP meeting with the entire team present.

- 8. Developmental status or diagnosis;
- 9. Program plan recommendations that address the child's holistic needs based on the evaluation;

- 10. A narrative description of all five (5) areas of a child's developmental status;
- (b) The full report shall be written in clear, concise language that is easily understood by the family.
- (c) The reports and notification of need for further evaluation shall be made available to the IFSP team within ten (10) working days from the date the evaluation was completed.
- (8) Child records of timely evaluations transferred from out of state tertiary centers or developmental evaluation centers may be utilized for eligibility determination;
 - (a) These records shall be reviewed for all required evaluation record components by the POE services coordinator;
 - (b) If information is unattainable, the child shall be evaluated for eligibility.

Section 2. Eligibility.

- (1) Children who are eligible for First Steps services include those who are ages birth through two (2), and:
 - (a) By using appropriate diagnostic instruments and procedures, or professional judgment, are determined to have fallen significantly behind developmental norms in the following skill areas:
 - 1. Cognitive development;
 - 2. Communication through speech and language development;
 - 3. Physical development including vision and hearing;
 - 4. Social and emotional development;
 - 5. Adaptive skills development; and
 - (b) Are significantly behind in developmental norms as evidenced by the following criteria:
 - 1. Two (2) standard deviations below the mean in one (1) skill area (developmental quotient equivalent seventy (70) percent or below); or
 - 2. At least one and one-half (1 1/2) standard deviations below the mean in two (2) skill areas; or
 - 3. Children may be determined to be developmentally delayed by professional, clinical judgement, in the event standard deviation scores are inconclusive and evaluation reveals the child has significant atypical development or quality or pattern of development, or further diagnostic evaluation is needed to address concerns related to the five (5) areas of development. Professional judgement to determine a child to be developmentally delayed shall be obtained from an approved evaluator; or

Best Practice Guideline: Professional, clinical judgement is reserved to the Intensive Clinics only.

- (2) Those children who are diagnosed with physical or mental conditions which have a high probability of resulting in developmental delay and the diagnosis has been specified by KRS 200.645(10) as an established risk condition. The developmental delay shall be within one (1) of the following categories:
 - (a) Chromosome abnormalities associated with developmental delay;

- (b) Recognizable syndromes associated with developmental delay;
- (c) Abnormality in central nervous system;
- (d) Neurological or neuromuscular disorders associated with developmental delay;
- (e) Symptomatic intrauterine infection or neonatal central nervous system infection;
- (f) Sensory impairments that result in significant visual or hearing loss, or a combination of both, interfering with the ability to respond effectively to environmental stimuli;
- (g) Metabolic disease having a high likelihood of being associated with developmental delay, even with treatment;
- (h) Maternal teratogen exposure at a level known to have a high risk for developmental delay;
- (i) Behavioral or emotional disorders associated with extreme excesses or deficits which inhibit function;
- (j) Central nervous system malignancy or trauma resulting in developmental delay.
- (3) Eligibility for a premature child shall consider:
 - (a) The chronological age of infants and toddlers who are less than twenty-four (24) months old shall be corrected to account for premature birth;
 - (b) Correction for prematurity is not appropriate for children born prematurely whose chronological age is twenty-four (24) months or greater.
 - (c) Documentation of prematurity shall include a physician, or nurse practitioner, report of gestational age and a brief medical history.
 - (d) Evaluation reports on premature infants and toddlers shall include test scores calculated with the use of both corrected and chronological ages. (23 Ky.R. 3133; Am. 3851; 4171; eff. 6-16-97; 25 Ky.R. 661; 1407; eff. 1-19-99.)

Best Practice Guideline: To determine prematurity status and evaluation procedure, a child's **gestational age**, **chronological age** and **corrected age** must be obtained.

- Gestational age is length of pregnancy. It is determined by a physician, nurse practitioner or midwife and/or obtained from the medical record and must be documented in the First Steps record.
- ♦ Chronological age is actual age from date of birth.
- Corrected age is Gestational age (in weeks) + chronological age(in weeks)- 40 weeks.

Total is then converted to months (a month always equals 4 weeks for the purpose of this calculation). For example: If an infant was born 6 month ago at 32 weeks gestation, using the formula, the child is considered 4 months corrected age(24 weeks + 32 weeks = 56 - 40 weeks = 16 divided by 4 = 4 months corrected age). If a child is 16 months old at 32 weeks gestation the child is considered 14 months corrected age(64 weeks + 32 weeks - 40 = 56 weeks = 14 months corrected age).

♦ Post-conceptual or conceptual age is how the child's age is reported until 40 weeks (term).

Full term is considered to be 40 weeks. If an infant was born 4 weeks ago at 32 weeks gestation (length of pregnancy), the infant is considered to be 36 weeks post conception age(32 + 4).

An infant is considered premature in First Steps if the infant has a gestational age, at birth, of **less than 37 weeks**. Infants who have reached 37 weeks gestational age or more are considered to be full term and these guidelines do not apply.

For Children 29 to 36 weeks gestational age:

- ♦ When a child with a **29 to 36 week gestational age** is referred for First Steps services before **4 months** corrected age, primary evaluation must be done at the Intensive Level Clinic. Many standardized tests for this age infant are not normed for these premature infants and are not reliable. The Intensive Level Clinic will determine eligibility using the method best suited for that child, including using **Professional Judgment which** is reserved for use by only the Intensive Level Clinics.
- ♦ When a child with a **29 to 36 week gestational age** is referred for First Steps services after **4 months corrected age**, a Primary Level Evaluator(PLE) skilled in the evaluation of premature infants may do evaluation.
- ◆ Testing protocols for a premature child with a chronological age (age from date of birth) of <u>less than 24</u>
 <u>months (2 years)</u> must be corrected to account for their premature birth. The PLE must report both sets of
 scores based on chronological and corrected ages. The <u>Battelle Developmental Inventory</u> is **not** correctable for
 prematurity, but can be used after the child is chronologically 24 months or older. Primary evaluators must
 check the test manual to be sure that the standardized testing method chosen can be corrected for prematurity.
 These tests often require considerable expertise and experience in order to be administered reliably. A mixed
 testing strategy must be applied in order to obtain scores in each of the five skill areas.
- ♦ Testing protocols for a premature child with a chronological age (age from date of birth) of more than 24 months (2 years) are not tested based on corrected age.

Best Practice Guidelines for children with 28 weeks or less gestational age:

If a child has a gestational age of 28 weeks or less:

- <u>with</u> Established Risk diagnosis refer to an Intensive Level Clinic for a five area assessment or intensive evaluation.
- ♦ <u>without</u> Established Risk diagnosis and are referred for First Steps services less than 9 months corrected age, child is determined eligible by Established Risk Extreme Prematurity(ICD- 9 code 765.0)
 - a. ISC obtains well child evaluation and documentation of gestational age from physician report, and
 - b. Consults with family and physician to determine if there are any current concern about developmental delay.
 - ♦ If developmental concerns exist, ISC refers to Intensive Level Clinic for a five area assessment or intensive evaluation
 - ♦ If no developmental concerns, ISC begins to develop monitoring program by:
 - 1. Consulting with family and physician on most appropriate choice of monitoring discipline, should be a DI, OT, PT, SP with considerable experience with premature infants, then
 - 2. Holds IFSP meeting inviting family, evaluator (intensive team member), and physician, PSC, monitoring discipline and any other identified team members to include:
 - a. PSC and 1 x/month visit by a monitoring discipline as a minimum to monitor child's progress and provide family support;
 - b. Assessment as necessary;
 - c. Referral to Intensive Level Clinic site for evaluation at 4 months corrected age, then re-evaluation at 8 months corrected age, or sooner if developmental concerns arise; and
 - d. PSC follows recommendations from the Intensive Level Clinic.
- ♦ Without Established Risk diagnosis and are referred for First Steps services between 9 months corrected age and 2 years old, should be referred to the Intensive Level Clinic site for a Primary Level Evaluation. If there is hardship or difficulty scheduling appointments at the clinic site, then a record review may be done. Before scheduling the Primary Evaluation, consult with the Intensive Level site on recommended tests, consents and records.

NOTE: If there is indication of a condition that might lead to an additional Established Risk diagnosis at any time; or the child's condition changes to the degree requiring additional attention, this recommended procedure should not be continued and immediate referral for further evaluation or assessment should occur at an Intensive Level Clinic Site. Call any Intensive Level Clinic Coordinator with any questions about premature children.